

**INSIDER, OUTSIDER, ALLY, OR ADVERSARY: PARENTS OF YOUTH WITH LEARNING DISABILITIES ENGAGE IN EDUCATIONAL ADVOCACY**

**Cheryll Duquette  
Stephanie Fullarton  
Shari Orders  
Kristen Robertson-Grewal**  
*University of Ottawa*

*The purpose of this qualitative study was to examine the educational advocacy experiences of parents of adolescents and young adults identified as having a learning disability (LD) through the lens of four dimensions of advocacy. Seventeen mothers of youth with LD responded to items in a questionnaire and 13 also engaged in in-depth interviews. It was found that the dimensions of advocacy provided a useful framework for understanding the participants' experiences and parents could be categorized as insiders, outsiders, allies, and adversaries with different advocacy outcomes.*

Advocacy is defined as *taking one's own or another's perspective to obtain a result not otherwise available* (Turnbull & Turnbull, 1997, p. 294). It occurs *any time people speak or act on behalf of themselves or others* and involves *presenting, supporting, or defending a position* (Alper, Schloss, & Schloss, 1995 p. 265; Turnbull & Turnbull, p. 297). In a recent study on the school experiences of adolescents with fetal alcohol spectrum disorder, four dimensions of parent advocacy emerged (Duquette, Stodel, Fullarton, & Hagglund, 2011b). The purpose of this study was to explore the educational advocacy experiences of parents of adolescents and young adults with learning disabilities (LD) with a view to extending the scholarship on parent advocacy by examining the phenomenon through the lens of the four dimensions.

Parents of children and youth with special needs have a formalized role that is enshrined in special education legislation across North America (Individuals with Disabilities Education Act of 1990 and its reauthorization in 1997; provincial legislation in Canada). They have a right to be involved in the decision-making process about their children, and it is expected that parents and school personnel will work as partners (Brown, Sigvaldason, & Bedner, 2005; Turnbull & Turnbull, 1998) in developing Individual Education Plans (IEPs). However, noted in the literature is that it is not typical practice for school personnel to invite parents to discuss issues related to the development of an IEP (DeFur, Todd-Allen, & Getzel, 2001; Thoma, Rogan, & Baker, 2001). Childre and Chambers (2005) argue that when parents are not involved in educational planning, the supports identified for the students may be inadequate. Not surprisingly, some parents want to have their voices heard in the decision-making process about what accommodations, programs, and services are provided by the school (Waggoner & Wilgosh, 1990). When they realize they have rights, that accommodations can help their child succeed, and that there are limits to resource allocations, many parents begin to advocate (Alper et al., 1995; Heiman & Berger, 2008). They are imbued with the sense that their advocacy will improve the quantity and quality of services delivered to their individual child (Gross, 1996; Heiman & Berger, 2000; Wang, Mannan, Poston, Turnbull, & Summers, 2004). Moreover, unless they feel supported by a teacher or school administrator, parents feel they are their child's only advocate (Wang, et al., 2004). The research shows that parents want to develop a partnership with the school that is based on open communication (Grove & Fisher, 1999; Hess, Molina, & Kozleski, 2006; Stephenson, 1992). Alper et al., (1995) identify communication with the educators as an important element of interpersonal advocacy, one of the four types of advocacy they propose.

The four categories proposed by Alper and her colleagues (1995) included self-advocacy, social support advocacy, interpersonal advocacy, and legal advocacy. They contend that interpersonal advocacy involves interactions by family members, professionals, or others on behalf of the child or youth with disabilities. This type of advocacy occurs most frequently through formal and informal communication and is the starting point for addressing the inequities of educational resource allocation on an individual basis. Formal communication occurs at specific times of the year, such as during the report card meetings and the annual review of the IEP. Informal communication is on-going and serves the purpose of preventing minor problems and developing trusting relations (Stephenson, 1992). Parents may communicate informally by sending a notebook to and from school or by making telephone calls to the school to ensure that there are no minor problems. They also informally educate the teachers about their children's exceptionality and help out in the classroom (Grove & Fisher, 1999). Building a positive relationship with the people who are responsible for providing the supports and accommodations for their children within the school setting is seen as important by parents (Hess, Molina, & Kozleski, 2006). Hence, continual communication is an important element of interpersonal advocacy that lays the foundation for an effective home and school partnership.

#### *Dimensions of Advocacy*

In a study involving the adopted parents of adolescents and young adults with fetal alcohol spectrum disorder (FASD) (Duquette, et al., 2011b), open communication was also noted as an important element of parent educational advocacy. However, it was shown in this research that educational advocacy may be viewed as having four dimensions that are awareness, seeking information, presenting the case, and monitoring. In the first dimension, *awareness*, parents became aware that their children were developing or functioning at an academic or cognitive level that was different from their peers through their own observations or reports from teachers. Parents may also have been informed of behaviour problems that were occurring at school. The second dimension is *seeking information* which involved learning more about the child's strengths and weaknesses through a formal assessment, the exceptionality named in the diagnosis, special education policies, and programs offered by the local boards of education and private schools. The most popular sources of information were websites (parent support groups and the boards of education), other parents, and printed resources (e.g., books, pamphlets, and articles). In the third dimension, the parents were engaged in *presenting the case* to educators. Their arguments for accommodations, resources, or special class placements were based on the formal assessment and they sometimes brought lawyers or trained advocates to help them argue their case. Other activities in this dimension included developing the IEP, attending the report card meetings and the yearly reviews. Informally, parents also tried to maintain open lines of communication and educate the teachers on their children's exceptionality and needs. In addition, some parents also lobbied politicians for programs and services. The fourth dimension is *monitoring* and the main task of the parents was to ensure that the accommodations listed in the IEP were provided. Parents kept an eye on their children's academic progress and how their children were feeling about school. If they were not doing well or were feeling frustrated, it might have been because the required accommodations were not being offered. Once parents became aware of potential problems, they sought further information and presented the case again to the school for the provision of the required accommodations.

In another study using the dimensions of advocacy with 17 parents of students identified as intellectually gifted, it was found that these dimensions are not discrete stages that a parent moves through in a lockstep pattern (Duquette, Orders, Fullerton, Robertson-Grewal, 2011a). As the initial process of identification, placement, and programming occurred at the school, parents assumed more of the activities of each dimension of advocacy without shedding any of the activities from the previous dimensions. Hence, it was possible that parents were performing tasks in all four dimensions simultaneously. However, this framework needs further testing with parents of children with other exceptionalities. Therefore, it was the purpose of this research to determine if the advocacy tasks performed by parents of adolescents and young adults with learning disabilities could be categorized according to the dimensions of advocacy.

#### **Method**

In this qualitative research the parents of adolescents and young adults with learning disabilities described their experiences as educational advocates within publicly funded boards of education in the Province of Ontario. In the next sections the methodology used in this study is described.

*Participants*

The participants consisted of 17 birth mothers of adolescents and young adults identified as having a learning disability who responded to an announcement placed on the website of the Learning Disabilities Association of Ontario. The selection criteria were that their child had to have a diagnosis of a learning disability and be enrolled in a high school or have recently graduated from secondary school. Six of the participants' children had a diagnosis of LD, seven had a dual diagnosis, three had a triple diagnosis, and one had a quadruple diagnosis. They were most often assessed with attention deficit hyperactivity disorder and/or giftedness in addition to learning disabilities. The adolescents and young adults were either in high school (9/17) or had graduated (8/17) and ranged in age from 14 to 27 years (see Table 1). Only one child had failed a grade (#9) and another youth left school without graduating (#1). There were 13 males and 4 females. Most of the parents indicated that they became aware that there were problems in the academic progress of their son or daughter in elementary school and they all had been advocating ever since.

**Table 1. Characteristics of Adolescents and Young Adults with LD**

Person	Sex	Age	Highest grade	High school placement	Parents aware	Diagnosis
1	M	20	Gr. 11 (working)	Special class	High school	LD
2	M	25	Gr. 13 (university)	Private school	7 yr.	NVLD, gifted
3	M	15	Gr. 10	Regular class, basic level	6 yr.	LD, language disorder
4	F	16	Gr. 11	Fr.Immersion +accommodations	Gr. 2	LD, ADHD
5	F	27	Gr. 13 (university)	Regular class +accommodations	Gr. 3	LD
6	M	17	Gr. 11	Regular class +resource support	Kindergarten	LD, CAPD
7	F	25	Gr.12 (university)	Private school	6 yr.	LD, ADHD, Scotopic sensitivity syndrome
8	M	15	Gr.10	Regular class +accommodations +resources support	Kindergarten	NVLD, gifted
9	M	16	Gr. 9	Adaptive high school program	3 yr.	LD, speech & language disorder
10	M	14	Gr. 8	Regular class	Kindergarten	LD
11	M	15	Gr. 9	Regular class +accommodations +resource support	1 yr.	LD
12	F	24	Gr.12 (working + college)	LD class	Kindergarten	LD
13	M	19	Gr.12 (college)	Regular class	Gr. 4	LD, ADHD, anxiety, Scotopic sensitivity syndrome
14	M	18	Gr. 12 (university)	IB program to Gr. 11, regular class for Gr. 12	High school	LD, ADHD, gifted
15	M	14	Gr. 8	Regular class +accommodations	Gr. 2	LD
16	M	21	Gr.12 (university)	Regular class +accommodations	Kindergarten	LD, ADHD, gifted
17	M	15	Gr. 9	Regular class +accommodations	Gr. 3	LD, ADD

*Data Collection*

Data were collected through questionnaires and individual interviews. The questionnaires consisted of open-ended items related to the four dimensions of parental advocacy, the assessment process, and the school experience of their children (see Appendix A). Participants were invited to be involved in an in-depth interview to discuss their advocacy experiences further (Marshall & Rossman, 2006). Thirteen of the mothers told their stories in semi-structured interviews that lasted about 60 minutes each. During that time, they were asked to elaborate on the questions to which they had responded in the questionnaire (see Appendix B). A transcript of each interview was prepared and sent to the participant for approval. A few

of the participants corrected the grammar and added more details to the transcripts and only approved transcripts were used in the analysis.

#### *Data Analysis*

The quantitative data were analyzed descriptively; however, most of the data were qualitative and were analyzed inductively. The data from the interviews and open-ended questions were read repeatedly, text was underlined, and notes were made (Miles & Huberman, 1994). They were organized into five categories of which four were the dimensions of advocacy. The fifth was the school experiences of the sons and daughters of the participants. The responses to the questions in each category were coded and examined for patterns that emerged as sub-categories. The categories and sub-categories are shown in Table 2. The data in the sub-categories assisted the researchers in understanding the school experiences and the specific activities performed by parents in each of the dimensions. The constant comparative method was used to saturate the sub-categories and interpretations were made using inductive reasoning (Patton, 2002). The analysis was done by hand to facilitate engagement with the data (Charmaz, 2000).

**Table 2. Categories and Sub-Categories**

Category	Sub-Category
Awareness	Mothers observed delays in language, trouble learning, anxiety and depression, similar characteristics in older siblings Teachers observed academic difficulties
Seeking information	Psychological assessment, LD, policies and procedures Mostly websites (support groups, Ministry of Education) Frequency: continually or when there was a problem
Presenting the case	Formal meetings sometimes with education advocates but not lawyers  Informal meetings – inservice the teachers, open communication, volunteering Elected as a trustee
Monitoring	Children's feelings about school, academics School's implementation of the IEP
School experiences of the Youth	Strengths, needs, and accommodations Factors contributing to success Factors hindering success

#### *Trustworthiness*

To establish the quality of the study, the researcher must describe indicators that provide evidence that the information generated in the research is trustworthy and believable (Freeman, deMarrais, Preissle, Roulston, & St. Pierre, 2007). The indicators in this study were credibility and transferability. Researchers seek to ensure that there is a correspondence between how the participants view the phenomenon and how they interpret the comments of the participants (Guba & Lincoln, 1989). Credibility was established by doing negative case analysis and member checks. Transferability refers to the extent to which readers assess the findings consistent or potentially consistent with their own experience or settings (Miles & Huberman, 1994). Transferability was enhanced by presenting much of the data supporting each category and sub-category, which would assist the readers to link the findings to their own situations. Additionally, the data were analyzed independently by the researchers, who were in agreement with the findings (Mertens, 2005).

#### *Findings*

The findings of this study are reported in this section and they were organized under three broad headings: school experiences of the youth with learning disabilities, the educational advocacy activities of the parents, and reflections on the advocacy experiences. The sub-section on reflections consists of major points about advocacy that were beyond the scope of the four dimensions.

### *School Experiences of the Adolescents and Young Adults with Learning Disabilities*

The data demonstrated that many of the adolescents and young adults were or had been in regular high school classes with accommodations and only two were placed in a special class or school. The participants' comments indicated that their children's academic problems were in reading and written expression and that the arts and athletics were areas of strength. According to the parents, the factors contributing to the academic success of these students with learning disabilities were individual characteristics, parents' actions, and institutions' actions. Individual characteristics identified by the mothers that contributed to success were their children's work ethic, determination to succeed, empathy, and caring nature. The participants also stated that their own actions were linked to the academic outcomes of their children. Specifically, at the school level they advocated for accommodations and at home they provided tutors (science, math, and English) and assistance with assignments. They also tried to develop their children's areas of strength through extracurricular activities. The actions taken by the institutions were the final contributing factor to academic success and the provision of accommodations was viewed as very important by the parents. The most common accommodation was extra time for exams and assignments, and six of the youth also had access to assistive technology, such as a laptop computer and Kurzweil reader. Additionally, at the school level, a few great teachers were acknowledged by participants in helping their children succeed.

Parents also identified factors that hindered success, such as the individual characteristics of their children (e.g., refusal of accommodations and assistance and their children's shy and anxious nature). Actions taken by schools were also cited as a barrier, such as a late or incorrect identification which in turn limited access to appropriate programs and accommodations. A participant explained that her son *did not receive a proper diagnosis [from the board of education] and was not properly supported in the school system*. She added, *If he had had the help beginning in the early years, he would not be as disabled as he is now*. It was also noted by a few parents that boards seemed to have difficulty supporting children with a dual diagnosis, such as a learning disability and giftedness. Other actions at the institutional level noted by parents were teachers who did not understand learning disabilities, did not follow the IEP and give accommodations, or had low expectations. These factors that hindered success were linked by parents to the withdrawal from high school by one adolescent and suicide attempts by two others. No parents identified factors related to them that hindered the academic outcomes of their child.

### *Dimensions of Advocacy*

In the next sections the findings on educational advocacy are presented. The data were categorized according to the four dimensions of advocacy and are described in turn.

**Awareness.** A few mothers noticed delays in receptive and expressive language when their children were preschoolers, but most of the participants stated that they became aware that their children may have a learning difference during elementary school. Some mothers observed that their son or daughter was having trouble learning and completing work in the primary grades, and about half of the participants reported that it was a teacher who informed them about problems in reading and math. Other mothers saw the signs of a learning disability when their children began elementary school because it was their second child and they knew what to look for. However, two mothers stated that they only became aware that there were problems when their sons were in secondary school. One of these parents wrote, *He began shutting down in class and at home.... [He had] terrible nightmares and refused to go to school*. Another mother explained that she became aware that her son may have a disability through her own observations and a suggestion by a teacher:

*So I kind of put these together in my head. The child is struggling, extremely frustrated, depressed, withdrawn, not happy, and we have these unexplainable issues. And then when the school said, Well why don't you get tested, I said, Okay, let's go.*

In sum, parents generally became aware that their children may have a learning issue in elementary school, and this was mostly due to lags in academic achievement. For parents whose children were not identified as having a learning disability until high school, it was the awareness of emotional issues related to school that lead to an assessment.

**Seeking information.** All but one parent sought information on their child's strengths, weaknesses, and how he or she learned. Many participants indicated that they thought a psychological assessment in which a formal diagnosis was indicated would be the first step towards obtaining appropriate

programming for their children. One parent stated, *I thought that if my son got the diagnosis he would receive the necessary help and the school would put him in the right place.* Most participants sought an assessment from a psychologist in private practice rather than the school board because it was felt that *parents must substantiate their child's needs from sources outside of the school board.*

Before the first meeting with school personnel to discuss the assessment, parents developed their procedural knowledge of the school system. The mothers sought information on their board of education's special education procedures, the range of program options offered by the board, home schooling, and the Ministry of Education policies. They also looked for information about learning disabilities to gain a deeper understanding of them, and as one mother said, *You've got to be knowledgeable because it's a complex area.* Most of the information came from websites (e.g., the Learning Disability Association), parent support groups, and informal parent sharing. Many mothers stated that they still seek information continually and a few indicated that they look for information only when there is a problem. A mother observed, *You know, there's always another issue and another problem. And there are always changes in philosophy and policy, and it's so time consuming to keep on top of all those sorts of things.* The participants learned that the task of seeking information is *a huge and constant challenge.* One mother who was also a board trustee explained, *Information does not come willingly from the school personnel ...the process is not parent friendly; [it's] very passive aggressive.* Hence, the parents in this study devoted time to doing their own research to find the information they needed to argue for the needs of their children.

*Presenting the case.* About half of the participants expressed difficulty convincing the school personnel that their son or daughter had a learning disability and required specific accommodations. However, a thorough report from a psychologist established the diagnosis and learning needs of the child. For the first meeting in which the psychological report was discussed, seven participants stated that they brought a psychologist or education advocate with them to argue their case. As noted by one mother, *professionals are necessary to explain and testify to the child's needs.* Another participant wrote she had no trouble convincing the board of education of her child's needs because *The report was extremely thorough (26 pages) and I had an LD advocate with me.* Education advocates from the support groups were invited by parents to attend the school meetings *to ensure that the IEP was a true reflection of [the child's] needs* and to support the parents *during this emotional time.* Interestingly, two of the mothers in this study had accompanied and supported other parents at these meetings. One of these participants was a psychologist and the other an educational advocate. Among parents who had sought support in presenting the case, the feeling was that it was generally helpful. A participant later regretted not inviting an advocate. She explained, *I naively thought that I did not need one as I trusted the school board. I was wrong.*

Most of the other parents commented that they had either considered inviting professionals or education advocates to the meeting but did not. A few mothers had someone review the IEP before the meeting and decided against inviting a support person. One parent explained, *I had an LD advocate review the IEP and was told it was a good IEP.* Another parent was a psychologist who understood the professional's report and the IEP, and she felt comfortable making the case on her own. The parents in this study did not recommend bringing a lawyer to any of the formal meetings with the school or board personnel. One mother's comment summed up the general feeling, *I do not feel lawyers belong at the [school level meeting].* It appeared that participants recognized that polite persistence with the people who were ultimately going to provide supports for their children was a better strategy than the threat of legal action.

All of the children had an IEP and the role of the mothers in preparing the first one ranged from no participation at all to actually writing it with the teachers. After the first IEP was written, parents continued to present their case for accommodations to individual teachers. Some mothers commented that they consistently had to remind the teachers of the need for accommodations at the yearly meetings when the IEP was reviewed. Many mothers also met with teachers at the beginning of each semester to go over the needs and accommodations for their children. Almost all of the participants indicated that it was also their role to educate the teachers about learning disabilities and the strengths and needs of their own children. A participant commented, *Many teachers were ill-informed about learning disabilities.* In response, they provided teachers with printed and electronic information, such as articles, pamphlets, and websites. Parents reported that meeting with teachers and providing them with information was necessary to raise their awareness of the needs of their sons and daughters, which they hoped would prompt the teachers to provide the much-needed accommodations.

For seven of the mothers, arguing the case also meant engaging in political action that involved phone calls and letters to trustees, superintendents, their board's Special Education Advisory Committee, Members of the Legislative Assembly, and the Ministry of Education. Additionally, as a result of their experiences making the case for their children, two of the participants were motivated to become trustees in their respective boards of education, which afforded them information and influence. One mother stated, *I ran for and was elected to the Board of Education when my daughter was in grade 6. I sat on and chaired the Special Education Advisory Committee. Through this I was very aware of my rights and the resources available.* Her position within the board, not only gave her access to information, but helped her garner the respect of teachers working with her daughter. When teachers had not read the child's file and were not providing the required accommodations, her questioning as a trustee and not as a parent prompted them to do so.

At times many of the mothers in this study seemed to be fighting an uphill battle with the schools about their children's need for accommodations. However, they persisted because they believed that their children's academic success depended on them presenting the case for accommodations that were vital to learning. One mother noted that this role was *time consuming and exhausting.*

*Monitoring.* Many mothers felt that teachers were not always willing to communicate to parents about the accommodations they are actually providing to their children. The concern was that it is *difficult to know if the IEP is being implemented without monitoring* because teachers *are not transparent about this at all.* Another mother stated that parental involvement and monitoring are necessary because *you cannot assume that your child is having success.* To gauge if the accommodations were being implemented and if the children were doing well academically, all of the mothers in this study monitored how their children were feeling about school. One mother commented that *if your child is unhappy, she will not do well in school.* They also indicated that they regularly monitored the academic progress of their son or daughter *because no one else will if I do not.* Some parents also wanted to keep their children's names fresh in the minds of teachers so that they were not forgotten or overlooked, particularly if the child was quiet and posed no behavioural problems. Parents believed that monitoring had to occur regularly and at the beginning of each semester because *if you wait until report card time, it's too late.*

For most parents monitoring involved talking to their child and communicating with the teachers at school with the hope of influencing their behaviours. However, having political clout reduced the amount of monitoring required at the school level. One mother who was a trustee was able to use her influence with teachers *who couldn't be bothered* to read her child's file and provide the accommodations listed on the IEP. With a single phone call, accommodations were in place. As shown, the participants in this study were conscientious mothers who monitored the situation at school to ensure that their children received the accommodations listed in the IEP and that school was a positive experience for their sons and daughters. As one mother explained, *He doesn't receive what is stated in the IEP unless we continually advocate.*

#### *The Advocacy Experience*

A theme that emerged from the data was the mothers' reflections on their advocacy experiences. Thoughts on the outcomes of advocacy, sources of information and support, and advice for other parents are presented. The participants indicated that despite the frustrations in working with the board of education and the schools, there were rewards for their advocacy efforts. All but one of the young adults had graduated from high school and all had enrolled in postsecondary education or were employed. Additionally, the adolescents who were still in school were academically on track to graduate. Over the years the participants found that the Internet was their most important source of information about learning disabilities and special education policies and procedures. The mothers also reported that support from others, such as parent groups had sustained them during the more challenging times. The few teachers who understood learning disabilities and were willing to assist were another source of support for them. One mother stated, *This last [resource] teacher has been really helpful by just taking an interest in my son.* Another source of comfort for some mothers was their own son or daughter, *realizing his strengths – he is responsible and creative.*

These mothers also had advice for other parents. They unanimously agreed that parents must advocate for their children in order to obtain accommodations and resources for their children. A mother who became a trustee stated,

*I have seen time and time again that the squeaky wheel gets the grease at all levels. Until there are changes in staff attitudes, adequate financing of special education programs and services, and good resources in place, parents will have to advocate for their children.*

Advocacy was seen as a long-term commitment requiring an ongoing investment of time, effort, and often money. Participants also advised other parents to provide emotional support for their children.

*Believe in their abilities even when they are struggling. It doesn't matter how hard something is for them, let them know they can do it. ... Once confidence is lost often motivation is lost with it, especially with a child who struggles with a learning disability.*

Participants further advised parents to build an alliance with the school so that teachers would be willing to provide accommodations. One parent stated, *I was supportive of the school and its staff and program, volunteering extensively. Because of this, teachers were willing to help me.* This statement reflects how dependent parents and children are on the good will of teachers to provide a supportive environment and the importance of becoming an ally. Hence, they cautioned other parents against taking an adversarial stance with the school: *Be an ally not an adversary.* Their final piece of advice was *never give up.*

### **Discussion**

In the present study, the educational advocacy experiences of parents of adolescents and young adults diagnosed with learning disabilities were explored using the lens of four dimensions of advocacy. The findings demonstrated that the participants' advocacy activities could be categorized according to the four dimensions. Consistent with previous research on the dimensions of advocacy, once these parents began advocating, they quickly became immersed in it and were performing tasks in all four dimensions simultaneously (Duquette, et al., 2011a). These participants also perceived learning disabilities as a difficulty that requires accommodations in order for the child to succeed (Heiman & Berger, 2008). As well, they were aware that their advocacy improved their children's chances of obtaining the accommodations and supports that met their children's needs (Gross, 1996). It was also understood that they were responsible for their child's progress in school and were sometimes their children's only advocate (Wang, et al., 2004). As shown in other studies, it was mainly the mothers within the family unit who were involved in the educational advocacy efforts (Lareau, 2002; Traustadottir, 1991).

A difference between these data and the findings of previous research with the dimensions of advocacy is that some of the participants entered the political arena. Not only were they able to speak to the needs of all students with special needs in their district, their political clout ensured that their voice was heard when they presented the case for their own children. As trustees working within the organization, they knew their rights and had access to information about resources. With this information they were able to influence the outcomes of the formal meetings with educators and ensure that IEPs were read and followed. There seemed to be a certain sense of accountability to a trustee that was not afforded to other parents. Mothers who were trustees were the insiders.

Most parents were outsiders who advocated at the formal meetings without a clear understanding of the resources that could be made available. Like the insiders, they informally tried to influence the thinking and behaviours of teachers, but they did so by building an alliance with them based on volunteering their time and communicating formally and informally (Alper et al., 1995; Grove & Fisher, 1999; Hess, et al. 2006; Stephenson, 1992). They were eager to develop a positive relationship with the school because they believed that the teachers' cooperation was essential to their children's academic progress. They participated in a type of social exchange (Grane, Kroeger, & Prager, 2001) in which they volunteered their time and communicated with teachers to obtain information and resources that would support their children. No matter how angry or frustrated they became, the parents understood the importance of maintaining positive relations with the school. These parents were outsiders who tried to develop an alliance with the school; however, unlike the insiders they were not always able to ensure that inflexible teachers provided accommodations or that their children had access to resources or programs.

So important was the school's cooperation that the participants cautioned against bringing lawyers to meetings because it would be an overly aggressive stance. These parents understood that it was up to the school to provide the accommodations for their children and they did not want to be viewed by the

school as adversarial. For an outsider, being an adversary could jeopardize the relationship with the school and the provision of accommodations and resources.

The data from this study suggest that educational advocacy and banking may be analogous. Credits are gained through communication and volunteering which builds a positive relationship between home and school. However, one dimension of advocacy, arguing the case, could have the effect of debiting the account, especially if the parent came on too forcefully or lawyers were present at the meetings. Participants in this study learned to use the adversarial approach sparingly so as to maintain a credit in the imaginary account and the good will of teachers who would be inclined to provide accommodations for their children.

#### *Conclusions and Implications*

The mothers in this research were wholly committed to ensuring a positive school experience for their children and they realized that a) their children required academic supports b) there was a relationship between advocacy, positive relations with the school, and resource allocation, and c) unless they advocated for their children, no one else would. For most participants, advocacy was a series of necessary activities that occurred throughout their children's elementary and secondary schooling. The findings of this research indicated that advocacy activities were organized into four dimensions.

There were two limitations of this research. The first is that there were only 17 participants and they were all from the province of Ontario. However, it is felt that there were sufficient data for readers to transfer the findings to their own situations. The second limitation is the data are restricted to information provided by parents and not educators. Although this study was confined to parents' perceptions, the inclusion of teachers and administrators in future studies would enrich our understanding of educational advocacy.

An implication for practice is the need for preservice and inservice education for teachers in the area of special education. Parents in this study felt that some teachers were insufficiently informed about specific exceptionailities and how to address dual exceptionailities. Parents seemed to link knowledge with understanding and caring, which motivated a teacher to provide accommodations. However, it should also be noted that a principal's support of a student's special needs may be instrumental in obtaining supports, especially in times of scarce resources.

Not all parents are insiders and there will always be limited resources and reluctant teachers, therefore, it would seem important for school boards to make special education policies and procedures transparent to the public. Additionally, parents should learn how to advocate on behalf of their children. An implication is for an expanded role for support groups that should ensure that information about rights and advocacy is available to all parents, particularly when school boards are not *transparent* and especially for those parents who are new to the system and may not understand their role. Moreover, support groups should develop and promote the service of providing educational advocates for parents who are unable to present the case for their children. Finally, support groups should spearhead advocacy efforts at the district and national/provincial level in order to increase the resources allocated for the needs of students identified with special needs.

Although further work is required to gain a more complete understanding of educational advocacy by parents of students with special needs, our findings contribute to our knowledge of the structure and context of the phenomenon of educational advocacy. Additionally, the findings provide support for the use of the framework of the four dimensions as a tool for analyzing and understanding educational advocacy from the perspective of parents who seek accommodations for their children who are educated in publicly-funded schools.

#### **References**

- Alper, S., Schloss, P., & Schloss, C. (1995). Families of children with disabilities in elementary and middle school: Advocacy models and strategies. *Exceptional Children*, 62(3), 261-270.
- Brown, J., Sigvaldson, N., & Bednar, L. (2005). Foster parent perceptions of placement needs for children with fetal alcohol spectrum disorder. *Children and Youth Services Review*, 27, 309-327.
- Charmaz, K. (2000). Grounded theory objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2<sup>nd</sup> ed., pp. 509-536). Thousand Oaks, CA: Sage.

- Childre, A., & Chambers, C. (2005). Family perceptions of student centered planning and IEP meetings. *Education and Training in Developmental Disabilities, 40*(3), 217-233.
- Defur, S., Todd-Allen, M., & Getzel, E. (2001). Parent participation in the transition planning process. *Career Development for Exceptional Individuals, 24*, 19-36.
- Duquette, C., Orders, S., Fullarton, S., & Robertson-Grewal, K. (2011a). Fighting for their rights: Advocacy experiences of parents of children identified with intellectual giftedness. *Journal for the Education of the Gifted, 34*(3), 488-512.
- Duquette, C., Stodel, E., Fullarton, S., & Hagglund, K. (2011b). Adolescents with fetal alcohol spectrum disorder and parental advocacy in education. *International Journal of Inclusive Education, Advance online publication. doi:10.1080/13603116.2011.557445*
- Freeman, M., deMarrais, K., Preissle, J., Roulston, K., & St. Pierre, E. (2007). Standards of evidence in qualitative research: An incitement to discourse. *Educational Researcher, 36*(1), 25-32.
- Grane, M., Kroeger, J., & Prager, D. (2001). Bakhtinian analysis of particular home-school relations. *American Educational Research Journal, 38*(3), 467-498.
- Gross, J. (1996). The weight of evidence: Parental advocacy and resource allocation to children with statements of special educational need. *Support for Learning, 11*(1), 3-8.
- Grove, K., & Fisher, D. (1999). Entrepreneurs of meaning: Parents and the process of inclusive education. *Remedial and Special Education, 20*(4), 208-215.
- Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation*. Newbury Park, CA: Sage.
- Heiman, T., & Berger, O. (2008). Parents of children with Asperger syndrome or with learning disabilities: Family environment and social support. *Research in Developmental Disabilities, 29*, 289-300.
- Hess, R., Molina, A., & Kozleski, E. (2006). Until somebody hears me: Parent voice and advocacy in special educational decision-making. *British Journal of Special Education, 33*(3), 148-157.
- Lareau, A. 2002. Invisible inequality: Social class and childrearing in black families and white families. *American Sociological Review, 67*(5), 747-776.
- Marshall, C., & Rossman, G. (2006). *Designing qualitative research* (4<sup>th</sup> edition). Thousand Oaks, CA: Sage.
- Mertens, D. (2005). *Research and evaluation in education and psychology* (2<sup>nd</sup> edition). Thousand Oaks, CA: Sage.
- Miles, M., & Huberman, M. (1994). *Qualitative data analysis: A sourcebook of new methods* (2<sup>nd</sup> ed.). Newbury Park, CA: Sage.
- Patton, M. (2002). *Qualitative research and evaluation methods* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage.
- Stephenson, J. (1992). The perspectives of mothers whose children are in special day classes for learning disabilities. *Journal of Learning Disabilities, 25*(8), 539-543.
- Thoma, C., Rogan, P., & Baker, S. (2001). Student involvement in transition planning: unheard voices. *Education and Training in Mental Retardation and Developmental Disabilities, 36*, 16-29.
- Traustadottir, R. (1991). Mothers who care. *Journal of Family Issues, 12*(2), 211-228.
- Turnbull, A. P., & Turnbull, H. R. (1997). *Families, professionals, and exceptionality: A special partnership* (3<sup>rd</sup> ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.
- Turnbull, H. R., & Turnbull, A. P. (1998). *Free appropriate public education: The law and children with disabilities* (5<sup>th</sup> ed.). Denver, CO: Love.
- Waggoner, K., & Wilgosh, L. (1990). Concerns of families of children with learning disabilities. *Journal of Learning Disabilities, 23*(2), 97-98, 113.
- Wang, M., Mannan, H., Poston, D., Turnbull, A., & Summers, J. (2004). Parents' Perceptions of advocacy activities and their impact on family quality of life. *Research & Practice for Persons with Severe Disabilities, 29*(2), 144-155.

## Appendix A

### PARENT ADVOCACY QUESTIONNAIRE: LEARNING DISABILITIES OR GIFTEDNESS

How old is your adolescent or young adult? \_\_\_\_\_

What is the sex of your child? (Please circle)      Female    Male

Who is answering this questionnaire? (Please circle)

Adoptive Mother | Adoptive Father | Birth Mother | Birth Father | Other (identify) \_\_\_\_\_

**A. Diagnosis and Identification of Learning Needs and Strengths**

1. How did you first become aware that your child might have a learning disability or have giftedness?

---

---

---

2. Has your child had a psychological assessment? Yes No

3. If yes to #2, what was the diagnosis?

---

4. If yes to #2, at what age was your child diagnosed? \_\_\_\_\_

---

---

---

5. If yes to #2, what led you to seek a diagnosis?

---

---

---

6. If yes to #2, from whom or what organization did you obtain a diagnosis?

---

7. What characteristics of learning disabilities or giftedness does your child display?

---

---

---

8. What community/health services have you received (if any)?

---

---

9. Has your child been identified by the board of education at an Identification, Placement, and Review Committee (IPRC) meeting as having an exceptionality?

Yes No

10. If no, to #9, why has there not been an IPCR?

---

11. If yes to #9, what exceptionality was identified?

---

12. If yes to #11, when did the first IPCR occur?

---

13. Did you have any difficulty convincing the school personnel that your son or daughter had a learning disability or giftedness? Yes No

14. If yes to #13, how did you convince them that your son or daughter had an exceptionality?

---

---

---

15. Does your child have an Individual Education Plan (IEP)? Yes \_\_\_\_\_ No \_\_\_\_\_
16. If yes to #15, when was the first one written? \_\_\_\_\_
17. What role did you play in preparing the IEP?  
\_\_\_\_\_  
\_\_\_\_\_
18. What are your child's academic strengths?  
\_\_\_\_\_  
\_\_\_\_\_
19. What are your child's academic weaknesses?  
\_\_\_\_\_  
\_\_\_\_\_
20. What other strengths or weaknesses does your child demonstrate (e.g., interpersonal skills, technical skills, artistic abilities, athletic abilities)?  
\_\_\_\_\_  
\_\_\_\_\_
21. Please write any further comments you would like to make about the diagnosis and IPRC procedures for your son or daughter over the years.  
\_\_\_\_\_  
\_\_\_\_\_
- B. Academic Progress**
22. In what type of high school program is/was your son or daughter enrolled?  
\_\_\_\_\_
23. What accommodations and/or program modifications does your child receive?  
\_\_\_\_\_  
\_\_\_\_\_
24. How important are the accommodations and/or program modifications to your child's academic success?  
\_\_\_\_\_  
\_\_\_\_\_
25. What is the highest grade your child has completed? \_\_\_\_\_
26. If he or she has completed high school, in what year did this occur? \_\_\_\_\_
27. Has your child repeated a grade? Yes \_\_\_\_\_ No \_\_\_\_\_
28. Has your child been accelerated a grade(s)? Yes \_\_\_\_\_ No \_\_\_\_\_
29. If yes to #27 or #28, which grade/s? \_\_\_\_\_

30. Has your child been suspended from school? Yes No

31. If yes to #30, how many times? \_\_\_\_\_

32. If yes for #30, for what reasons?  
\_\_\_\_\_

33. Does your child have a transition plan (a plan for transition to employment or postsecondary studies)? Yes No

34. If yes to #33, what plans are proposed?  
\_\_\_\_\_

35. Has/did your child discussed dropping out of high school? Yes No

36. If yes to #35, what is the stated reason(s)?  
\_\_\_\_\_

37. If yes to #35, what keeps/kept him or her in school?  
\_\_\_\_\_

38. Did your child drop out of school? Yes No

39. If yes to #38, has he or she thought of returning? Yes No

40. If yes to #38, what is keeping him or her from returning?  
\_\_\_\_\_

41. What career aspirations does your child have?  
\_\_\_\_\_

42. Have you discussed possible careers with your son or daughter? Yes No

43. Have you discussed the steps necessary to reach the career goal with your son or daughter (e.g., required education, relevant work or volunteer experience)?

Yes No

44. Has your son or daughter received career counselling from the school?  
Yes No

45. Has your son or daughter received vocational training or participated in co-op, or work experience programs organized by the school? Yes No

46. If yes to #45, describe the training and its usefulness.  
\_\_\_\_\_

47. If no to #45, describe what type of training or experience would you have liked for your son or daughter?  
\_\_\_\_\_

48. Has your son or daughter taken post-secondary education/training? Yes No

49. If yes to #48, in what area and at what institution?

---

50. Was it useful? Why or why not?

---

---

---

51. If your son or daughter is no longer in school, what is he or she doing now?

---

---

52. For your child, what would be a successful school experience?

---

---

---

53. Please write any comments you would like to make about the academic progress of your son or daughter over the years.

---

---

---

### C. Seeking Information

54. In which of the following areas have you sought information to help you advocate for your son or daughter (please check).

- |                                     |       |
|-------------------------------------|-------|
| Learning disabilities               | _____ |
| Giftedness                          | _____ |
| Other schools                       | _____ |
| Other programs offered by the board | _____ |
| Home schooling                      | _____ |
| IPRC procedures (Parent Guide)      | _____ |
| Board policies                      | _____ |
| Other (please list)                 | _____ |

55. What were your sources of information (e.g., websites, Parent Guide, informal parent sharing, parent support group, etc.)?

---

---

56. Do you belong to a parent support group associated with your child's exceptionality? Yes No

57. If yes to #56, to which association(s) do you belong?

---

58. Did you seek information to help you advocate before the first IPRC? Yes No

59. When do you seek information now (e.g., before each yearly meeting, whenever there is a problem, constantly, etc.)?

60. Please write any further comments you would like to make about seeking information for use when advocating for your child's needs.

---

---

---

---

#### D. Presenting the Case

61. On what occasions do you present the case about your son or daughter's need to school personnel (e.g., at the yearly review meeting, during the report card interviews, etc.)?

---

62. Have you ever brought a representative of the parent support group or a lawyer to the meetings?

Yes                  No

63. If yes to #62, why did you invite this person?

---

64. Did this person help you achieve the outcomes you desired for your child?

Yes                  No

65. If no to #62, why have you not invited a representative of the parent support group or a lawyer to the meetings?

---

66. Do you meet with the teachers at times other than the IPRC review meeting to discuss your son's or daughter's accommodations or program modifications as they are written in the IEP?

Yes                  No

67. If yes to #66, how often?

---

68. Do you try to educate the teachers about learning disabilities or giftedness?

Yes                  No

69. If yes to #68, how do you do this (e.g., providing lists of websites, pamphlets, etc.)?

---

70. Have you lobbied politicians about the needs of students who have learning disabilities or who are gifted?      Yes                  No

71. If yes to #70, state who the politicians were (e.g., trustees, MLA) and describe the actions you took.

---

---

72. What have you learned about presenting the case for your son or daughter to school personnel?

---

73. Please write any further comments you would like to make about presenting the case to school personnel.

---

---

**E. Monitoring**

74. Do you monitor how your son or daughter is performing academically in school?

Yes                  No

75. Do you monitor how your son or daughter is feeling about school?

Yes                  No

76. Do you monitor if the accommodations and/or program modifications are being implemented?

Yes                  No

77. If yes to # 74, 75, or 76, how often do you monitor the above?

---

78. Do you monitor other aspects of the school program in which your son or daughter is involved?

Yes                  No

79. If yes to #78, what are these aspects?

---

---

80. Why do you engage in the monitoring discussed in the previous questions?

---

---

81. Please write any further comments you would like to make about monitoring.

---

---

---

**F. Other**

82. Do you provide assistance to your child to complete homework or assignments/projects?

Yes                  No

83. If yes to #82, under what conditions and how frequently do you provide help (e.g., most nights, only when asked)

---

---

84. Does your son or daughter have a tutor?

Yes                  No

85. If yes to #84, for which subjects is he or she receiving tutoring?

---

86. Have you talked to your son or daughter about how to self-advocate?

Yes                  No

87. List the 3 aspirations you have for your child.

---

---

---

88. List the 3 most important concerns you have about your child and his or her future.

---

---

---

89. What has been most helpful to you as a parent of a child with learning disabilities or giftedness?

---

---

---

90. What are the factors that have contributed to your son's or daughter's success?

---

---

---

91. What are the factors that have hindered your son's or daughter's success?

---

---

---

92. What advice do you have for parents of children with learning disabilities or giftedness?

---

---

---

---

93. Please write other comments about your child with learning disabilities or giftedness and your experiences raising him or her.

---

---

---

---

---

---

**Thank you for your time and the information you have provided. Please mail this questionnaire within one week of receiving it using the envelope that is provided.**

If you would like to participate in an interview to discuss your experiences as an advocate for your child's needs, please complete the section below.

Name: \_\_\_\_\_  
Evening Telephone Number: \_\_\_\_\_  
Daytime Telephone Number: \_\_\_\_\_  
E-mail Address: \_\_\_\_\_

## Appendix B

### Parent Advocacy Interview

1. Tell me about the process in which your son/daughter was assessed by a psychologist.
2. How did you feel about the diagnosis?
3. What did you know about learning disabilities/giftedness before the assessment?
4. Tell me about your first experience with an Identification, Placement, and Review Committee (IPRC)?
5. Did you participate in developing the IEP? If so, how did you assist?
6. Were you satisfied with the level of participation and the experience in general?
7. What accommodations or program modifications does/do your son or daughter require?
8. Were they written in the psychological report? Did you have to fight to have them included in the IEP?
9. How is your son/daughter progressing in school?
10. What would be the ideal program for your son or daughter?
11. How do you seek information when advocating? (e.g., Internet, support group)
12. When do you seek information, for example before the annual IPCR review meeting?
13. Do you attend the IPCR review meeting? How do you prepare for it?
14. Do you meet with teachers at times other than the IPCR review meeting? What is the purpose of these meetings? How do you prepare for them?
15. Have you lobbied politicians? If so, for what? Describe your experiences. (With the support group? How did you prepare? What happened when lobbying? Were you successful?)
16. Do you monitor your son/daughter's progress in school? How do you do this?
17. What do you do if your son/daughter's progress is not what is expected or your child is frustrated?
18. What things have hindered your progress when advocating for your son/daughter's educational needs?
19. What things have facilitated your progress when advocating for your son/daughter's educational needs?
20. What suggestions do you have for parents who advocate?
21. Please make any other comments you would like about your experiences advocating.